

Date: 04/07/2017

FREEDOM OF INFORMATION REQUEST FOI/013502 – Amyloidosis

I am an Italian researcher and I am writing a paper on Amyloidosis in Europe.

I am looking for information regarding the diagnosis and/or treatment of this rare disease in UK hospitals beside the national reference centre for it (NAC).

I was wondering if you have any public data on any of the following points:

- number of confirmed diagnoses of Amyloidosis in this NHS trust (and in which hospital and possibly department/consultant) in the last year -

The Trust does not record in an electronic form when a new diagnosis is made and we do not record the diagnosis of an outpatient attendance. We do record the diagnosis codes for an admitted care episode.

There were patients who were discharged with a primary diagnosis of Amyloidosis but due to the low numbers (single figure number) and to avoid any harm or distress to the patients in being potentially identified in the public domain the Trust is not disclosing the number of patients

- number of currently treated Amyloidosis patients in this NHS trust (and in which hospital and possibly department/consultant) in the last year –

- number of currently MGUS (monoclonal gammopathy of undetermined significance) patients treated in this NHS trust (and in which hospital) in the last year -

- number of currently treated MM (Multiple Myeloma) patients in the last year -

The Trust does not clinically code 'treatments'. We clinically code diagnoses and procedures.

Any treatment information is held within a patient health record, which is exempt information under section 40 personal information of the FOI Act